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Development of a questionnaire to determine change in the occupational performance of pre-school children with autistic spectrum disorders receiving occupational therapy - sensory integration

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Chapter 1
INTRODUCTION

The prevalence of autism is on the increase worldwide. Autism is a developmental disorder and currently there is no known cure (Allik, Larsson, & Smedje, 2006; Rutter, 2005a; Fombonne, 2003; Powell, Edwards, Pandit, Sungum-Paliwal & Whitehouse, 2000). Parents with newly diagnosed young children are faced with a multitude of wide-ranging treatment options many without definitive research evidence. However, multidisciplinary early therapeutic intervention is regarded by experts as a cornerstone of treatment (Schaaf & Mulrooney, 2007).

The stress associated with parenting a pre-school child with an autistic spectrum disorder (ASD) is high, due to the delays in occupational performance, and the need for parents to continually manage difficult behaviour. The typical occupations of children of pre-school age, which include play, activities of daily living and peer interaction, depend on sensorimotor foundations (Jasmin, Couture, McKinley, Reid, Fombonne, & Gisel, 2009). In the typically developing child Piaget's sensorimotor period is the first stage in social-cognitive development. Sensorimotor exploratory activities influence perceptual learning and the establishment of a firm sensorimotor foundation. They are therefore essential for normal development to progress (Wadsworth, 2003). The occupational performance deficits, (Myers & Johnson 2007; Miller-Kuhaneck, 2004; Schaaf & Smith-Roley, 2005) and the sensory processing differences in children with ASD, (Ben-Sasson, Hen,Fluss, Cermak, Engel-Yeger, & Gal, 2008) are well documented.

Poor functional independence is related to and caused by atypical sensory responses and motor difficulties (Jasmin et al. 2009). The lack of normal sensorimotor development in the pre-schooler with ASD affects all aspects of occupational performance, resulting in poorly developed play skills, inappropriate peer interaction, poor adjustment to family life and extended dependence in daily living activities like delays in toilet training, sleep disturbances and feeding issues (Rodger, Braithwaite & Keen, 2004; Coster, 1998; Parham & Fazio, 1997; Trombly, 1993).

Thus children with this type of chronic disability have a huge impact on their families, especially their mothers (Fombonne, Simmons, Ford, Meltzer & Goodman, 2001).

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Parents of children with ASD were found to have higher rates of psychological distress than parents of children with other developmental disabilities (Fombonne et al. 2001). Autistic spectrum disorder has an even more profound impact than any other developmental disability due to the delays in occupational performance (Jasmin et al. 2009; Myers & Vipon, 2007) and the emotional and social components which are key elements of the disorder (Eisenhower, Baker & Blacher, 2005; Konstantareas & Homatides, 1989). Children with ASD frequently have poorly regulated sleep-wake cycles, resulting in parental sleep deprivation (Krakowiak, Goodlin-Jones, Herz-Picciotto, Croen & Hansen, 2008; Liu, Hubbard, Fabes & Adam, 2006). Their needs frequently compromise the ability of the rest of the family members to pursue their chosen occupations (DeGrace, 2004). The family's social life becomes circumscribed due to the child's difficulty in coping in multi-sensory environments, and difficulties with transitions and changes in routines (Kinneally, Koenig & Heuker, 1999).

Parents request occupational therapy (OT) in order to address their children's occupational performance deficits (Baranek, 2002). Ninety five to ninety-seven percent of occupational therapists choose a sensory integration frame of reference to steer therapy with young children with ASD, to address the problems in sensory processing and occupational performance in the USA (Case-Smith & Miller, 1999). Occupational Therapy using a Sensory Integration frame of reference (OT-SI) concentrates on the sensory (information) processing and the resultant effect on occupational performance in all areas. Ayres (1972) always intended that sensory integration be firmly embedded in the context of a full OT programme (Polatajko, Kaplan & Wilson, 1992).

Occupational therapy using a sensory integration frame of reference has been shown to have the potential to address many of the problems manifest in children with ASD. To date studies on young children with ASD who received OT-SI are predominantly single-subject research designs, measuring change in variables over time. A reduction in sensory defensiveness, especially tactile defensiveness, and in repetitive behaviour, was seen in a group of ten children with mild to severe autism in a retrospective longitudinal study (Ayres & Tickle, 1980). Gains in social interaction, response to movement, approach to new activities, response to being hugged or held and in activity level was seen in two pre-schoolers with ASD (Linderman & Stewart, 1999).

In another study, an increase in functional behaviours such as spontaneous speech, purposeful play and attention to activities and conversation was noted by independent

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raters using videos pre and post-treatment and a standardised functional assessment scale (Linderman & Stewart, 1999). Improvements in goal-directed play and engagement in activities was noted by independent evaluation using videos after ten weeks of OT-SI in a single–subject study using an AB design (Case-Smith & Bryan, 1999).

Thus the outcomes of occupational therapy can be assessed in the improvement in the child's and family's occupational performance and participation. Providing rich sensory opportunities in a playful, occupationally relevant context, with the "just right challenge", which facilitates "adaptive responses" (Ayres, 1972) and changes in brain functions and behaviour, has been identified as a basis for therapy with these children. Practitioners and families have come to appreciate the need for a deeper understanding of the ways in which the neurological process of sensory integration affects, and is affected by, participation in the occupations which can give structure and meaning to children's and their families' lives (Parham, 2002).

Management of the condition should therefore focus not only on the child, but also on the family (Myers & Johnson, 2007). Successful occupational therapy links the child and the family unit (Diggle, McConachie & Randle, 2003; Cohn & Cermak, 1998). Family-centred intervention, as opposed to child-centred treatment, thus focuses on addressing the child's emotional dysregulation and challenging behaviour, since it affects the entire family's occupational participation (Cohn, Miller & Tickle-Degnan, 2000). The wellbeing of the family depends on the functioning of the whole system, as well as on the functioning of each family member.

1.1 Statement of the Problem

Occupational performance outcomes for children with ASD that are important for parents have not been documented. This is because research has not documented the effect on the occupational performance of a pre-school child with ASD receiving sensory integration therapy, as the measures employed usually evaluate progress in terms of sensorimotor performance skills.

Progress in OT is difficult to measure, partly due to the inability of this population group to cope with standardised tests, and because no outcome measure of change in the child's occupational performance exists. There is therefore a need to develop and document the

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efficacy of interventions that aim to normalise sensory responses and improve motor and occupational performance skills in children with ASD (Jasmin et al. 2009).

Even though children with ASD attend occupational therapy amongst other therapies, the effect of OT-SI on the child's occupational performance with respect to family life is not known. A relationship between some of the occupational performance areas of the pre-school child with ASD and family functioning in terms of family life and relationships has been recorded in a number of studies (Davis & Carter, 2008; Jasmin et al. 2009; Donovan, van Leit, Crowe & Keefe, 2005; DeGrace, 2004). However no study considers all the areas of occupational performance in the pre-school child with ASD, there is no measure of the outcomes which reflects the change in the child and the family's broader occupational performance.

1.2 Research Question

Can a reliable and valid tool be developed to :

1. Measure the change in the occupational performance of pre-school children with ASD who receive occupational therapy using OT-SI?
2. Can the tool be validated in terms of change in the children's sensory processing and change in parenting stress?

1.3 Aim of the Study

To develop a valid and reliable outcome measure that occupational therapists can use to collect data and thereby determine the change in occupational performance functioning of the pre-school child with ASD who receives OT-SI.

1.3.1 Objectives of the Study

The objectives of this study are:

1. To design an outcome measure to determine the occupational performance of pre-school children with ASD, including questions to evaluate the parents' perception of how this affects the family's function in terms of lifestyle and relationships.

2. To determine the content validity and the reliability of the outcome measure.

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3. To determine consequential and construct (convergent) validity of the outcome measure in assessing the occupational performance in children with ASD by establishing the relationship between the scores for their occupational performance and scores measured by other standardised outcome measures assessing:
   - a component external to the child – the parents' stress levels over a 9-12 month period using the Parent Stress Index – Short Form (PSI-SF) (Abidin, 1995).
   - a component internal to the child – the child's sensory processing over a 9-12 month period using the Sensory Profile: Short Form (SSP) (Dunn, 1999).

4. To establish the responsiveness of the outcome measure to changes in occupational performance and its suitability as an outcome measure for data collection in terms of the change in functioning, during a 9 -12 month period while the child is receiving OT-SI:
   - by comparing the change in occupational performance of pre-school children with ASD to the change in their sensory processing as measured by the SSP
   - by comparing the change in the parent's perception of the impact change in the child's occupational performance had on the family, to the change in the parents' stress as measured by the PSI-SF.

1.4 Relevance of this Study

In line with international trends, the incidence of children diagnosed with ASD in urban areas is increasing in South Africa (Jacklin, 2006). The limited services available to pre-school children with ASD and their families is a concern that needs to be brought to the attention of the Health and Education authorities.

The researcher is concerned that the outcomes of OT-SI, in terms of changes in the child's occupational performance, are not recognised. The relationship between changes in the occupational performance of a child with ASD and the family's quality of life as reflected in the parents' stress levels as well as changes in the child's sensory processing may also lay the foundation for further study on the efficacy of OT-SI.

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The researcher intends that through this study a valid assessment tool will be developed. The assessment would measure outcomes of OT-SI in relation to occupational performance leading to an increased awareness of the benefit of addressing occupational performance as an early intervention strategy with this age group.

The relationship of changes in occupational performance in children with ASD in terms of other outcome measures will also be established allowing therapists to offer more inclusive family-centred occupational therapy.

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